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A PARENT'S TEARS: PRIMARY RESULTS FROM THE TRAUMATIC EXPERIENCES AND RESILIENCY STUDY

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ABSTRACT

This study examined health/mental health status, family functioning, and resiliency among a sample of bereaved parents ($N = 503$). Participants were recruited from an online support community to complete an online survey instrument (response rate = 51.75%). The questionnaire contained an array of self-report instruments, such as the Hopkins Symptoms Checklist-25 (HSCL-25), the Impact of Event Scale-Revised (IES-R), and the Family Assessment Device (FAD), as well as open-ended questions. Many respondents scored over the clinical cut-off for the HSCL-25 (51.3%, $n = 258$) and IES-R (42.3%, $n = 213$). IES-R scores were negatively correlated with years-since loss ($r = -0.24$, $p < .05$). In narrative responses, participants described a wide range of deeply impactful mental and physical health problems. The results indicate significant clinical distress in this sample of bereaved parents, with many reporting enduring psychological, familial, and health consequences following the death of a child.

INTRODUCTION AND OVERVIEW

The death of a child is recognized across cultures as one of life's greatest and most interminable tragedies, and bereaved parents have been the subject of scientific inquiry at an increasing rate. Using the PsychINFO database (Proquest version), we searched the psychological literature for articles on bereaved parents (using search terms "parents" AND "bereaved" or "bereavement" or "child death," peer-reviewed articles only, all fields) from 1960-present. From 1960-69, there were only 97 articles published; from 1970-79, 350 articles; and from 1980-89, 846 articles. From 1990-99, the number of articles rose to 1250; and from 2000-present, the number has skyrocketed, to 4,797 articles. Despite the burgeoning interest in this subject, biopsychosocial adaptations remain dimly understood within this population.

The psychological impact of bereavement can be substantial, especially in the case of child death. Sanders (1979-1980) found that at 2.2 months post-loss, grieving parents had higher grief reactions as compared to those who suffered conjugal or parental loss, with despair a prominent feature (see also Leahy, 1992-1993). At long-term follow-up, mothers who lose a child to stillbirth, SIDS, or neonatal death have higher rates of depression and anxiety compared to controls (Boyle, Vance, Najman, & Thearle, 1996; Turton, Evans, & Hughes, 2009). Rogers, Floyd, Seltzer, Greenberg, and Hong (2008) found an increase in long-standing depressive symptoms combined with a diminished sense of well-being and purpose in bereaved parents, lasting several decades beyond the death of a child. A Danish case-control study found an increased risk of suicide completion in bereaved parents (Qin & Mortenson, 2003). This was strikingly high in the first month after loss of a child; the odds ratio for completed suicide among men was 34.68 (95% CI = 19.31, 62.29) and for women was 76.05 (95% CI = 26.64, 217.08). While the increased risk of suicide fell over time, it remained elevated at ≥ 5 years post-loss (e.g., for women, OR = 1.86, 95% CI = 1.25, 2.77). Another observational study from Denmark (Li, Lauresen, Precht, Olsen, & Mortensen, 2005) found an increased risk of psychiatric hospitalization following the death of a child (RR = 1.67, 95% CI = 1.53, 1.83).

Researchers have also frequently observed a negative health impact on parents after child's death (e.g., Murphy, Lohan, Braun, Johnson, Cain, & Beaton, 1999; Rostilla, Saarela, & Kawachi, 2011), although there are also conflicting studies that do not find this association (e.g., Birnbaum, Stewart, & Phillips, 1996; Li, Johansen, & Olsen, 2002). Among the studies that do identify an association is a large-scale epidemiological study reporting an increase in premature mortality rates for bereaved mothers (HR = 1.43, 95% CI = 1.24, 1.64). The authors suggest that "pathophysiological changes related to stress could increase susceptibility to infectious diseases, affect the risk and prognosis of cancer, and lead to diseases of the cardiovascular system . . . increasing smoking and alcohol intake, altering dietary patterns, and reducing physical activity" (Li, Precht, Mortensen, & Olsen,

2003, p. 366). Bereaved parents with physical health problems are more likely to have co-occurring mental health difficulties as well; bereaved mothers with poor self-reported health status were 4.6 times more likely to also report trauma symptoms (Murphy et al., 1999).

While some studies refute the role of child death on divorce (Schwab, 1998), other studies suggest that child death may, indeed, have a substantially negative impact on family and marital functioning. Rogers et al. (2008) found that a group of bereaved parents had higher rates of marital disruption (30.4%) than a comparison group (23.8%). One large study with a nationally represented sample of 3461 women found a significantly increased risk of marital dissolution in parents experiencing stillbirth, infant, and child death that did not extend to infertility and miscarriage (Shreffler, Hill, & Cacciatore, 2012). Beyond marital distress, family functioning in general is adversely impacted by the death of a child (Lohan & Murphy, 2002).

Researching parents who have experienced child death is sensitive, often logistically complex. Because they are a vulnerable population, care for clients must be prioritized over data collection. In an increasingly electronic culture, those with myriad conditions often seek social support in online support groups. The content of such groups can be a rich source of data (e.g., Swartwood, Veatch, Kuhne, Lee, & Ji, 2011). Survey research that recruits participants from online support communities has many potential advantages; participants have already begun to voluntarily share their experiences; they are personally invested in the topic, and they are more likely to find the topic salient. A potential disadvantage of surveying online support groups is that, in terms of demographics, participants tend to be homogenous—largely white, relatively affluent, and educated (i.e., Eun-ok, Chee, Lim, Guevara, Tsai, Clark, et al., 2007).

Although there are many available online support communities for bereavement, there are few surveys of participants from these communities. Feigelman, Gorman, Beal, and Jordan (2008) found that 72.1% of participants in an online support group for suicide survivors were currently depressed. Yet, there is a clear gap in the literature in that there are no surveys of participants in Internet support communities that focus specifically on parental bereavement. We thus conducted a survey research project (TEARS: Traumatic Experiences and Resiliency Study) examining this understudied population, surveying participants of support forums of a non-profit organization which serves bereaved parents. Specifically, we sought to describe this sample in terms of demographics, psychological distress, family functioning, health status, and resiliency.

METHOD

We conducted a cross-sectional online survey of online support forum participants from June to October of 2010. This online forum launched in 1997 and now offers 27 different forum boards moderated by nine volunteers trained by the

nonprofit agency. As of 2010, 5,955 individuals had registered for these forums at some point.

The online survey contained a combination of questions created to collect information on the respondent as well as several validated measures commonly used in research on mental health, family functioning, and resiliency. Given the sensitivity of the topic, we pilot-tested the survey by administering to a small group of individuals who had experienced bereavement, some of whom were academic researchers, and incorporated the feedback into the final version of the survey. The survey was then placed on the World Wide Web using Qualtrics survey software. The survey utilized skip-logic, whereby participants were asked some questions only if they met criteria set by a specific question. Thus, respondents were exposed to a variable number of questions; depending on their answers, participants answered from 167-209 individual items.

The forum membership database listed 1120 participants active from 2009-2010, with 972 valid e-mail addresses. We first sent an e-mail solicitation containing a link to the online survey, which resulted in 313 responses. We followed with a series of further efforts, spaced several weeks apart; a reminder e-mail, a video message from the agency, and the offer of a \$20 gift card incentive for participating. These follow-up efforts generated an additional 190 responses. We received a total of 503 responses, resulting in a final response rate of 51.75%. All but nine respondents (99.83%) were mothers or fathers who had suffered the death of a child; seven respondents were grandparents, one was an aunt, and one indicated "other." Because of their close relationship with the child who died as caregivers, we chose to include these individuals in our analyses and refer to the overall sample as "parents."

Measures

Demographics and Circumstances of Loss

In order to describe the characteristics of the sample, respondents were asked a series of questions regarding demographics and the circumstances of their loss. These included gender, age, race/ethnicity, income, educational level, and religion. Respondents were also asked if the child's death was unexpected, whether they were present when their child died, if they witnessed the death, if they saw the child after death, and if they held/touched the child after he/she died. Several temporal questions were asked which allowed the calculation of time-since loss.

Mental Health Functioning

As a gauge of psychiatric history, and to contextualize the other mental health measures (see below), we asked "In the months before the loss, were you diagnosed with any mental health condition?" and "Were you taking psychiatric

medications at the time of your loss?" Participants then took several validated mental health measures.

Hopkins Symptoms Checklist (HSCL-25): The HSCL-25 (Derogatis, Lipman, Rickels, Uhlenluth, & Covi, 1974) is a 25-item self-report instrument that contains both anxiety and depression subscales. Respondents were asked to identify the degree to which they had experienced each symptom on a 4-point scale ranging from "not at all" (1) to "extremely" (4). In order to classify clinical cases, we used a cut-off of > 1.75 (average score). This has performed well in identifying depression; research with women found a sensitivity of 0.81 and a specificity of 0.70, and for panic and generalized anxiety disorder, a sensitivity of 0.67 and specificity of 0.73 (Sandanger, Moum, Ingebrigtsen, Dalgard, Sorenson, & Bruusgaard, 1998).

The Impact of Event Scale-Revised (IES-R): The IES-R is a self-report measure which asks respondents to rate 22 difficulties (for example "I felt irritable and angry") to gauge how distressing each particular area has been over the past 7 days. Answers are recorded on a 5-point scale ranging from "not at all" (0) to "extremely" (4), and the IES-R is scored by averaging item responses. There is no agreed upon clinical cut-off for the IES-R (Weiss, 2004), although various cut scores have been proposed and tested, and the IES-R is sometimes used to identify clinical cases (e.g., Samuelson, Lundberg, & Fridlund, 2007). We chose to use an IES-R total score cut-off of 33 (average score of 1.5). Using the 1.5 cut-off, Creamer, Bell, and Faira (2003) found that the IES-R had "... a sensitivity of 0.91, a specificity of 0.82, positive predictive power of 0.9, and negative predictive power of 0.84" (p. 1494).

Drug and alcohol use: In order to assess for a post-loss increase in drug/alcohol intake, we asked respondents, "Did you increase your drug or alcohol consumption after the death?" Those who answered "yes" to this question were administered the alcohol and drug use section of the self-report Addiction Severity Index (ASI; see Rosen, Henson, Finney & Moos, 2000).

Physical Health Status

Participants were asked, "Has your physical health significantly changed since your loss?" and could answer in response that their health: (a) has improved since the loss, (b) has remained the same since the loss, or (c) has declined since the loss. Participants were also asked an open-ended follow-up question, "Please explain how your health has changed since the loss."

Family Functioning

The General Functioning subscale of the Family Assessment Device (FAD), was administered. This 12-item self-report instrument measures family functioning on a 4-point Likert scale according to the seven dimensions of the McMaster

Model of Family Functioning (Epstein, Bishop, & Levin, 1978). The FAD has established psychometric properties (Miller, Ryan, Keitner, Bishop, & Epstein, 2000; Tutty, 1995), and discriminates between psychiatric and non-clinical families (Miller et al., 2000). In addition, one open-ended item asked, "How has your loss affected your relationships with your spouse or partner and children?" to allow respondents to provide more specific descriptions regarding their family functioning since loss.

Resilience and Coping

The Posttraumatic Growth Inventory (PTGI) was administered to understand how respondents may have reconstructed their lives in positive ways as a result of the loss (Tedeschi & Calhoun, 1996). The PTGI is a 21-item instrument that measures respondents' perceptions regarding their ability to positively reconstruct their lives following a traumatic event. The PTGI uses a 6-point Likert scale, and the instrument's internal consistency was reported as .90 in one study (Tedeschi & Calhoun, 1996). The scale measures perceived changes on the following components: new possibilities, relating to others, personal strength, spiritual change, and appreciation of life. A limitation of the PTGI data in the present study relates to the personal strength subscale; one item was not transferred to the online survey correctly, leaving it out of the administration. The total score was calculated without the self-reliance item. In addition to the PTGI, participants were asked about their choices to engage in helping behaviors. Specifically, the survey asked respondents about whether they attended support groups, counseling, and/or engaged in volunteerism after the death of their child.

Statistical Analysis

The data were analyzed using PASW version 20.0 (SPSS Inc., Chicago, IL). There was a low proportion of missing data; ~5% for HSCL-25 and IES-R, ~10% for PTGI and FAD. A few respondents filled out the majority of the standardized measures but did not answer every item (e.g., on the IES-R, 16 respondents missed one item). Such missing values were replaced using mean imputation to generate scale/subscale totals. In the overwhelming majority of cases, only one item was replaced. Other than this use of within-scale mean imputation, we did not replace other missing data, and we present available-case analyses (Pigott, 2001). The years-since-loss variable was highly positively skewed and was normalized through logarithmic transformation.

Our primary goal was to describe this unique sample in some detail. To accomplish this, we use descriptive statistics (primarily measures of central tendency), proportions, and bivariate correlation, as well as narrative summaries of open-ended questions. Due to the nature of our data (a non-random survey of a population, albeit one with a robust response rate), our results should be interpreted descriptively rather than inferentially (Berk & Freedman, 2009). We report

95% confidence intervals for all major quantitative findings using the definition of confidence interval forwarded by Rothman (2003). To calculate confidence intervals for proportions, we used the Wilson (1927) method with continuity correction (Newcombe, 1998). When reporting percentages for categorical variables, we use the denominator of $N = 503$, our total sample; some variables do not sum to 100% due to missing data.

Procedure

The TEARS questionnaire was of substantial length, and space constraints do not allow the presentation of all data in one manuscript; in order to report the results in sufficient detail, other manuscripts will be generated. Here, we concentrate on describing the characteristics of our sample, primarily in terms of mental/ physical health and family functioning. The survey also contained questions about the economic costs of bereavement (which all participants were administered), as well as psychiatric medications (only administered to a subsample). These data analyses, which are substantial enough to preclude including them here, are reported in separate manuscripts (i.e., Lacasse & Cacciatore, in press; Fox, Cacciatore, & Lacasse, in press). Finally, this study was approved by the Institutional Review Board of our academic institution, by the ethics committee of the participating nonprofit organization, and all respondents gave informed consent.

RESULTS

Description of the Sample

The sample was overwhelmingly female (95.0%, $n = 478$) and white (85.7%, $n = 431$). Most responses came from the United States ($n = 390$, 77.53%) or from United Kingdom, Australia, or Canada ($n = 42$, 8.34%). Almost all respondents with missing data on this question connected through a U.S.-based server. Respondents resided mostly in suburban areas ($n = 238$, 47.3%), followed by rural ($n = 122$, 24.3%) and then urban ($n = 95$, 18.9%) residency.

Educationally, 48.5% ($n = 262$) of the sample had completed college degrees at the bachelors or graduate level, while 32.2% ($n = 162$) had attended some college or technical school, and fewer than 3% had not completed high school (see Table 1). Almost 70% ($n = 350$) identified as Christian, while 16.9% ($n = 85$) selected "no religious affiliation." In terms of categorical annual household income, 13.1% ($n = 66$) earned < \$28,000 annually, with 15.7% ($n = 79$) earning between \$28,001-\$50,000, and 17.5% ($n = 88$) earning between \$50,001-\$75,000. The remaining respondents (46.3%, $n = 217$) all earned > \$75,000 a year (see Table 1).

Table 1. Characteristics of Sample

Variable	<i>n</i>	%	95% CI	<i>Min</i>	<i>Max</i>	<i>M (SD)</i>	95% CI
Race							
Caucasian/White	431	85.7	[82.3, 88.6]				
African American	5	1.00	[0.4, 2.40]				
Latino	18	3.6	[2.2, 5.7]				
Native American	3	0.6	[0.16, 1.9]				
Asian	1	2.2	[1.6, 4.0]				
Mixed Race	9	1.8	[0.9, 3.5]				
Other	1	0.20	[0.01, 1.3]				
Age at loss				17.0	67.00	33.41 (8.50)	[32.64, 45.17]
Age at survey				18.07	70.22	37.74 (8.80)	[36.95, 38.53]
Years-since-loss				00.43	41.48	4.31 (4.31)	[3.94, 4.72]
Sex							
Female	478	95.0	[92.7, 96.7]				
Religious Affiliation							
Christian	350	69.6	[65.3, 73.5]				
Jewish	12	2.4	[1.4, 4.1]				

Muslim	1	0.2	[0.01, 1.3]
Other	55	10.9	[8.5, 14.0]
No affiliation	85	16.9	[13.8, 20.5]
Current Household Income			
Under \$28,000	66	13.1	[10.4, 16.5]
\$28,001-\$50,000	79	15.7	[12.7, 19.3]
\$50,001-\$75,000	88	17.5	[14.3, 21.2]
\$75,001-\$90,000	52	10.3	[7.9, 13.4]
\$90,001-\$125,000	84	16.7	[13.6, 20.3]
> \$125,000	81	16.1	[13.1, 19.7]
Level of Education			
Graduate Degree	102	20.3	[16.0, 24.1]
Bachelor Degree	142	28.2	[24.4, 32.4]
Some College	162	32.2	[28.2, 36.5]
H.S. Diploma	41	8.2	[6.0, 11.0]
< H.S. Diploma	12	2.4	[1.3, 4.3]

Note: CI = confidence interval; *Min* = Minimum value; and *Max* = Maximum value.

Experiences with Loss

Many respondents (43.1%, $n = 217$) reported witnessing the death of their child, while 16.3% ($n = 82$) reported that they were present at the time of death but did not witness it. Most (88.3%, $n = 444$) reported that they saw their child after death, and 84.7% ($n = 426$) reported that they had held or touched their child after death. The death was unexpected for most respondents (77.7%, $n = 391$), while 11.3% ($n = 57$) reported that the death was expected, and 7.8% ($n = 39$) reported that the death was both expected and unexpected. The death of a baby to stillbirth was commonly reported in this sample ($n = 215$, 42.7%). At the time of the survey, respondents had a mean age of 37.74 years ($SD = 8.8$), with a mean time-since loss of 4.31 years ($SD = 4.31$).

Mental Health Functioning

Few respondents (15.1%, $n = 76$) reported they were diagnosed with mental health conditions in the months preceding the loss. The most common diagnoses were depressive (11.7%, $n = 59$) and anxiety (7.8%, $n = 39$) disorders. Three (0.6%) respondents reported attention-deficit hyperactivity disorder, and six (1.2%) reported a diagnosis of bipolar disorder. Sixty-three participants (12.5%) were taking psychiatric medications at the time of death.

The HSCL-25 was completed by 478 participants, resulting in a Cronbach's alpha of 0.96. The mean average score on the overall instrument was 1.96 ($SD = 0.71$); for the depression subscale, $M = 2.10$, $SD = 0.77$; and for the anxiety subscale, $M = 1.74$, $SD = 0.73$. More than one-half (51.3%, $n = 258$) scored > 1.75 on the overall HSCL-25, while 57.9% ($n = 291$) scored > 1.75 on the depression subscale, and 36.6% ($n = 184$) scored > 1.75 on the anxiety subscale. Among participants ≤ 12 months post-loss who had not been diagnosed with a mental disorder at the time of loss ($n = 61$), 69.2% ($n = 45$) were clinical cases according to the overall scale, 73.8% ($n = 48$) by the depression subscale, and 52.3% ($n = 34$) on the anxiety subscale (see Table 2).

Four-hundred-eighty-three respondents completed the IES-R and the instrument exhibited a Cronbach's alpha of 0.95. The mean average score was 1.46 ($SD = .90$) for the overall instrument; for the subscales measuring intrusion, avoidance, and hyperarousal, subscale means were, respectively, 1.92 ($SD = 1.03$), 1.07 ($SD = .86$), and 1.37 ($SD = 1.19$). Less than half of respondents (42.3%, $n = 213$) scored above the clinical cut-off of 1.5. Respondents with years-since-loss of ≤ 12 months who were not diagnosed with mental disorder at the time of loss had a 63.1% ($n = 41$) rate of clinical caseness per IES-R of 36.5% ($n = 125$).

In order to examine the potential impact of a previous mental health diagnosis preceding the loss on our results, we performed an influence analysis (Rothman, & Greenland, 1998) by removing respondents who reported they were previously

diagnosed with a mental disorder ($n = 76$) and then re-performed these data analyses. There was no clinically significant change in any of the results; they changed only slightly (e.g., IES-R > 1.5 changed from 42.3% to 40.3%).

Roughly one-quarter of respondents (25.6%, $n = 129$) reported an increase in drug and alcohol use after the death. The mean number of days in which these participants drank alcohol in the past 30 days was 9.84 ($SD = 9.04$); for drinking alcohol to intoxication, 4.25 days ($SD = 4.43$); and for the number of days in which alcohol was self-identified as a problem 2.94 days ($SD = 3.94$). Only eight participants (1.6%) were “considerably” or “extremely” bothered by their alcohol problems in the last 30 days, and, similarly, ten respondents reported that treatment for alcohol problems was “considerably” or “extremely” important to them. Eighteen (3.6%) bereaved parents reported that they had used cannabis in the last 30 days; other drug use, such as amphetamines, was rare, with < 5 respondents reporting such use. Only three people (0.6%) reported that they were “considerably” or “extremely” troubled/bothered by a drug problem.

One-third of participants (33.8%, $n = 170$) reported a decline in their health since the loss, while 46.9% ($n = 236$) reported no change and 13.01% ($n = 66$) reported improvement. Those reporting a post-loss degradation in health status named a range of problems. Weight gain was common (10.5%, $n = 53$), and, like many of the reported health conditions, was often presented in the context of intermingled physical health symptoms and mental distress. Many reported a relationship between demoralization and weight gain and that in the wake of the loss, it was difficult to continue healthy lifestyle habits. For instance, “I’ve gained lots of weight and basically don’t care too much about my health,” while another wrote, “I have stopped caring for my body in any significant way. I do not exercise or even leave the house very often, whereas I used to be very active. . . . I have gained a great deal of weight. . . .” Another reported physical health symptom was daytime fatigue (6.6%, $n = 33$). Typical responses were “I’ve become lethargic and weak . . . I’m tired a lot” and “I am more much more tired and feel worse (physically) on a daily basis.” It was common for participants to describe varying clusters of health problems that had significant impact on their quality-of-life. For instance, “Developed high blood pressure, lost then gained weight, developed psoriasis, heart palpitations, [and] headaches” and “Have developed stress-induced migraines, a heart condition, and panic attacks.” Some participants reported their immune system seemed to worsen post-loss, with frequent illness a problem.

Family Functioning

Respondents on the General Functioning subscale of the FAD reported an overall mean score of 1.82 ($SD = 0.58$; $N = 437$), suggesting a reasonable level of family functioning for this sample. However, 31.6% ($n = 138$) scored above the 2.0 cutting score suggesting those respondents perceived their families’

Table 2. Mental Health and Family Functioning Measures

Instrument	<i>n</i>	%	95% CI	<i>Min</i>	<i>Max</i>	<i>M (SD)</i>	95% CI
Average Score-HSCL							
Overall				1.00	4.00	1.96 (0.71)	[1.90, 2.02]
Depression				1.00	4.00	2.10 (0.77)	[2.03, 2.17]
Anxiety				1.00	4.00	1.74 (0.73)	[1.68, 1.81]
Average Score-IES-R							
Overall				0	4.0	1.46 (0.90)	[1.38, 1.54]
Avoidance				0	3.9	1.07 (0.85)	[1.00, 1.15]
Intrusion				0	4.0	1.92 (1.03)	[1.82, 2.00]
Hyperarousal				0	4.0	1.37 (1.19)	[1.27, 1.48]
Clinical Cases HSCL-25							
> 1.75 Overall	258	51.3	[46.9, 55.7]				
> 1.75 Depression	291	57.9	[53.4, 62.2]				
> 1.75 Anxiety	184	36.6	[32.4, 41.0]				
Clinical Cases IES-R							
> 1.5 total avg. score	213	42.3	[37.0, 45.8]				
FAD							
> 2.0	138	31.6	[27.3, 36.2]	0	3.75	1.82 (0.58)	[1.77, 1.87]
PTGI							
Relating to Others				7	22	22.06 (6.58)	[21.46, 22.65]
New Possibilities				5	25	14.22 (5.07)	[13.74, 14.68]
Personal Strength				3	15	10.10 (3.36)	[9.71, 10.32]
Spiritual Change				2	10	5.74 (2.74)	[5.5, 5.98]
Appreciation of Life				3	15	10.0 (3.16)	[10.21, 10.79]

Note: All percentages are calculated using the denominator of *N* = 503, the total sample, except for the FAD, which uses *N* = 437, the number of responders who lived in a family situation.

functioning to fall within the clinical range (Table 2). The responses to the open-ended items ($n = 420$) regarding post-loss family relationships were consistent with the FAD results. The responses suggest that while many families were functioning well, others have experienced negative effects to their relationships as a result of the loss. Many respondents (45.5%, $n = 191$) reported the death of child caused a negative effect on their relationships with their spouse or partner. One participant stated, "My loss was heartbreaking for all of us, and we all dealt with it on our own and not together. I feel it has caused distance between [me and] my spouse." Similarly, another stated, "I feel that losing our child has cost us everything. Not only the incredible boy that we lost suddenly without warning, but our roles in our marriage, in our family. I feel we are strangers now, we don't know how to be close." Some responses suggested that couples had difficulty in communication and intimacy after the loss.

Others spoke about the challenges the death brought about in their relationships with their children. For example, one mother stated, "I tried to become closer to them [the children], but it is difficult. I find I smother them instead. I have found that we aren't truly together. That each person in the world is truly alone and we just happen to share space with other individuals." Another parent shared, "I have been somewhat leery of getting closer to my boys for the thought they, I may lose them as well. I have since gotten over this feeling and now find I am extremely overprotective of them for fear that something may happen to them." The comments related to increased challenges in parent-child relationships described an escalation in overprotectiveness and the fear of losing another child as hindering closeness with their current children.

Despite these negative appraisals, many respondents (54.5%, $n = 229$) reported that their relationships improved post-loss. For example, one respondent stated, "My relationship with my husband has only gotten stronger. We communicate more openly and have come to realize how important we are to one another." Similarly, another wife explained, "It has brought my husband and I closer, because I feel that he's the only other person in the whole wide world EVER who will know EXACTLY how I feel." A father agreed stating, "My son who died was the closest companion that I have ever had, next to my wife. I believe that the death of my son brought us [husband and wife] closer together." Thus, while the loss caused reduced communication and intimacy for some, for these couples, the death of their child seemed to have the opposite effect. Several respondents also noted improvements in parent-child relationships, noting an increased appreciation for their children. One wrote, "My relationship with my children is good. I feel closer to them. I feel a new sense of connection to my living children since her death." Similarly, another explained, "I value them [the children] more. I realized how much of a miracle my first son is after losing my second. I cherish the time spent with my family and try to make the most of it." Overall, findings suggest most of the families in this study perceived positive family functioning despite the death of a child. Yet, a substantial subsample did identify negative

effects to partnered and parent-child relationships which they attribute to the death of their child.

Resilience and Coping

The mean scores on the PTGI subscales are as follows: relating to others ($M = 22.06$, $SD = 6.6$); new possibilities ($M = 14.22$, $SD = 5.07$); personal strength ($M = 10.02$, $SD = 3.36$); spiritual change ($M = 5.74$, $SD = 2.64$); and appreciation for life ($M = 10.0$, $SD = 3.16$). These scores suggest that, overall, respondents experienced positive changes after loss to a moderate degree. The highest mean score was on the appreciation of life subscale, suggesting that bereavement can bring about a positive shift in perspective for some.

Despite the challenges these parents faced, evidence of resilience and efforts to engage in positive coping activities were also commonly discussed. Help-seeking behaviors in this sample were notable. Sixty-three percent of the sample indicated that they were aware of grief support groups offered in their communities, while 34.4% were unaware of them. Many participants (42.3%) indicated that they attended a grief support group. Reported attendance at support groups ranged from 1 to 200 sessions, with a sample mean of 9.4 sessions ($SD = 22.15$).

Most bereaved parents in this study (53.5%; $n = 269$) reported attending at least one counseling session with a trained mental health professional. Reported counseling attendance ranged from 1 to 250 sessions with a sample mean of 20.8 sessions ($SD = 40.18$). Participants were asked to rate the “helpfulness” of counseling on a 6-point scale where higher scores indicated more helpfulness. The mean score of this item was 4.49 ($SD = 1.42$), with 56.7% of respondents indicating that counseling was “helpful” or “very helpful,” and only 17.2% indicating that it was “very unhelpful” or “unhelpful.”

In addition to support groups and counseling, volunteerism and other prosocial behaviors are activities that can help others while also helping oneself. In this study, 182 respondents (36.2%) indicated that they had volunteered in their communities before their loss, while 225 (44.7%) reported volunteering after their loss. Specific volunteer activities included leading a support group, providing peer counseling or support, public speaking, community event organizing, fundraising, and/or financial contributions to help others.

Bivariate Correlations

Table 3 lists bivariate correlations between primary study variables. There was a statistically significant correlation between years-since-loss and both IES-R and HSCL-25 scores. These correlations were all negative; for instance, -0.24 for the total IES-R ($p < .05$). This equates to a r^2 value of 0.04, or 4% of variance in HSCL-25 scores explained by years since-loss. FAD scores had almost no correlation with years-since loss, ($r = -0.01$, $p > .05$) while the PTGI was positively correlated. The FAD was positively correlated with the IES-R and HSCL-25.

Table 3. Pearson Correlations Between Primary Study Variables

	YSL-Log	IES-R	IES-R-I	IES-R-A	IES-R-H	HSCL	HSCL-D	HSCL-A	FAD	PTGI
YSL-Log	—									
IES-R	-.24*	—								
IES-R-I	.31*	.92*	—							
IES-R-A	-.19*	.81*	.57*	—						
IES-R-H	-.20*	.93*	.84*	.64*	—					
HSCL	-.20*	.80*	.74*	.56*	.84*	—				
HSCL-D	-.21*	.78*	.73*	.55*	.80*	.97*	—			
HSCL-A	-.14*	.72*	.64*	.51*	.77*	.91*	.78*	—		
FAD	-.01	.23*	.16*	.22*	.25*	.29*	.32*	.20*	—	
PTGI	.19*	-.16	-.11*	-.15*	-.16*	-.17*	-.23*	-.05	.26*	—

Note: *N* ranges from 459-483. YSL-Log = Logarithmic transformation of years-since-loss; IES-R-I = intrusion subscale; IES-R-A = avoidance subscale; IES-R-H = hyperarousal subscale; HSCL-D = depression subscale; HSCL-A = anxiety subscale. For the General Functioning Subscale of the FAD, we used the final score, where lower numbers indicate better family functioning; for all other measures, we used scale and subscale totals.

**p* < .05 (2-tailed).

DISCUSSION

We have described in detail a sample of bereaved parents ($N = 503$) who participate in an online support community. The sample is overwhelmingly white and female, not uncommon in bereavement research (e.g., Caciatorre, 2007) especially when the sample is largely composed of women who suffered a baby's death to stillbirth as in our data ($n = 215$, 42.7%). These online bereaved parents, an understudied population, have been described across a broad array of biopsychosocial variables, including health, mental health, and family functioning.

One strength of our study is the use of validated mental measures. The HSCL-25 and IES-R results indicate that although few were diagnosed with mental disorder prior to their loss, many in this sample have enduring and significant emotional and mental health difficulties. The mean HSCL-25 overall score was 1.96 ($SD = 0.71$), with higher scores on the depression subscale ($M = 2.1$, $SD = 0.77$) than on the anxiety subscale ($M = 1.74$, $SD = 0.73$). The majority of the sample ($n = 291$, 57.9%) scored above the clinical cut-off of > 1.75 on the depression subscale, and assuming that the HSCL-25 performs adequately as a screening tool (Sandanger et al., 1998) this indicates a high prevalence of depression in this sample using this standardized measure. By comparison, the 12-month prevalence of depression is ~8.3% in the general population of the United States (Kessler, Bimbaum, Shahly, Bromet, Hwang, McLaughlin, et al., 2010).

In previous studies (Zisook, Chentsova-Dutton, & Schuchter, 1998), depressive symptoms co-occurred with anxiety and trauma. A substantial minority (42.3%, $n = 213$) scored > 1.5 on the IES-R. Although the IES-R is not a measure of DSM-IV defined PTSD, this cut-off score has been found to perform reasonably well diagnostically, and IES-R scores are highly correlated with the PTSD Checklist (0.84; see Creamer, et al., 2003). In a Japanese study, a slightly lower cut-off score (1.36) was validated through clinical interviews (Asukai, Kato, Kawamura, Kim, Yamamoto, Kishimoto, et al., 2002), and it is possible that using a cut-off of 1.5 led to reduced sensitivity in our study, as 21 cases (4.1%) had IES-R average scores between 1.36 and 1.49. Despite this arguably conservative approach, a substantial proportion of respondents were clinical cases according to their IES-R scores. This high prevalence exceeds that found in studies of burn victims (Palmu, Suominen, Vuola, & Isometsa, 2010) and ICU survivors (Griffith, Fortune, Barber, & Young, 2007, p. 1514). It is also higher than the 27.7% rate of PTSD found in mothers who lost a child to violent death at 5-year follow-up (Murphy, Johnson, Chung, & Beaton, 2003) and a study of low-income mothers impacted by Hurricane Katrina which found that 32.7% had IES-R scores > 1.5 at ~4-year follow up.

We examined a subsample of respondents without a mental health diagnosis at the time of loss at ≤ 1 year since the loss. On the HSCL depression subscale, 73.8% were clinical cases, while on the IES-R, 63.1% exceeded the clinical-cut off. The 12-month incidence rates of PTSD and depression in the general population are

estimated to be 3.5% and 1.75-2.5%, respectively (Breslau, 2009; Bromberger, Kravtiz, Matthews, Yuok, Brown, & Feng, 2009). Our estimate is not a 12-month incidence proportion, as it is based on a cross-sectional assessment. However, it does suggest that, in our sample, the incidence proportion is no lower than what we have reported. While the sensitivity and specificity of the instrumentation should be considered, these data confirm that child death often leads to significant distress in both the short and long-term.

The relationship between traumatic bereavement and negative mental health consequences is a long-standing finding in the bereavement literature. Leahy (1992-1993) found that bereaved mothers scored significantly higher on depression measures than did bereaved adult daughters or widows, reporting symptoms such as sadness, sense of failure, guilt, suicidal ideation, self-image changes, work difficulty, and negative self-appraisal. Sanders' (1979-1980) found that bereaved parents experience intense and enduring somatic, psychological, and social consequences. The death of a child is a disaster, and human reactions to disaster are very complex, with emotional, cognitive, and biological effects. Shalev (2000) suggests that disaster, coupled with separation from the object of love and affection, can incite features of depressed mood, intrusive thoughts, pining, numbing, and severe separation distress. These features, as exemplified in the data reported here, are congruent with previous studies, suggesting that for many bereaved parents, emotional, somatic, and behavioral symptoms may endure long-term (Arnold, Gemma, & Cushman, 2005; Gillis, Moore, & Martinson, 1997; McCarthy, Clarke, Ting, Conroy, Anderson, & Heath, 2010). At the same time, we did find a correlation between years-since-loss and mental health status, although the clinical significance could be argued, since the coefficient of non-determination was ≥ 0.95 . A clinically significant impact of time upon anxiety and depressive symptoms in parental bereavement has been noted; in a population-based follow-up study, Kreicbergs, Valdimarsdottir, Onelov, Henter, and Steineck (2004) found the risk of anxiety and depression was equivalent to controls at 7-9 years post-loss.

The high prevalence of depression and anxiety in this sample based on these measures should be contextualized. Surveying members of an online support group entails an unavoidable selection bias (Rothman & Greenland, 1998). Individuals who are struggling with mental health issues following bereavement are potentially more likely to participate in an online support community. Interestingly, the prevalence of depression in our sample (73.8%) is similar to that self-reported by participants in an online support group for suicide survivors (72.1%, see Feigelman et al., 2008). Our mental health findings document the difficult struggles of an important and understudied subpopulation, but should not be generalized.

A minority of participants self-reported that their health had declined since the loss of their child (33.8%, $n = 170$), while most reported either level or improved health (60.0%, $n = 302$). These results should be interpreted in light of the fact that the mean time-since-loss was 4.31 years, with a mean respondent age of

36.69 years. Health status often declines with age and the mean age of participants indicates many respondents moving toward middle age. Thus, it is not possible from these data to isolate a casual impact of child loss upon health status. However, many of the respondents reported clinically important health problems subsequent to their loss, often co-occurring with anxiety, trauma, and depression. Researchers continue to document an association between psychological trauma and poor physical health (e.g., Boscarino, 2008), and it is likely that this association exists in our sample as well.

One-quarter of participants reported increasing their alcohol and/or drug use after the loss; however, with a mean of 4.31 years-since-loss, it appears many such increases were self-limiting in that few current substance abuse problems were reported. However, the subsample that reported increasing drug/alcohol use drank to intoxication 4.25 days a month; surveys of women in the general population find that only 1.73% of white women drink to intoxication > 3 times a month (Caetano, Baruah, Ramisetty-Mikler, & Ebama, 2010). This suggests that alcohol consumption among bereaved parents is perhaps a matter of clinical concern. Indeed, self-medication with alcohol among traumatized individuals is a well-recognized phenomenon (McFarlane, 1998), with potential ramifications for both physical and mental health.

Findings related to family functioning are consistent with the family resilience literature as they suggest some families are able to cope effectively and even grow stronger with this devastating loss while others continue to struggle (Lietz, 2012; Walsh, 2002). Although the death of a child represents one of the most painful experiences a family can have, this study demonstrates variability in functioning. While some families are clearly struggling, as indicated in the open-ended responses, many families are able to mitigate the risks. Family resilience literature suggests this variability can be explained by the presence of protective factors that allow family systems to cope effectively. Previous research has identified social support, spirituality, appraisal, flexibility, humor, and communication as protective factors that can explain how some families survive trauma and loss better than others (DeFrain & Asay, 2007; Lietz, 2007, 2012; Walsh, 1996, 2002). Further research should test models of family resilience to identify family strengths specifically indicated for bereaved families.

When taken together, our data demonstrate the significant and frequently enduring negative impact of losing a child. What is striking is that this has occurred to this sample in the context of having access to resources that are ideally of help. Respondents were well-educated, white, middle-class women with good incomes and sufficient health insurance, who seek and receive help through support groups and therapists. More than one-half of respondents reported benefits of counseling. Our results may indicate that our current system of care for and understanding of bereaved parents is inadequate, and that providers could be doing more to help grieving parents cope. There are no easy remedies, but problem-solving efforts should include addressing macro-level problems in mental health (Gomory,

Wong, Cohen, & Lacasse, 2011), improving clinical care in the immediate wake of child death (Cacciatore, 2010), and improved education and training for aspiring clinicians (Kirchberg & Neimeyer, 1991; Wass, 2004).

We are concerned that these data could lead to systemic pathologizing of bereaved parents. The common degree of distress may be viewed by some as indicative of a mental disorder, or, alternatively, the normal and common expressions of a profoundly traumatic and life altering loss (Cacciatore & Thielemann, 2012). We favor the latter interpretation and believe critical thinking regarding diagnosis is earnestly necessary—indeed, the frequency and intensity of reported distress raises the question of what is “normal” for a bereaved parent. We prefer these results not be interpreted as a call for more aggressive psychiatric diagnosis or drug treatment, the utility of which is questionable (Bui, Nadal-Vicens, & Simon, 2012).

As with any study, interpretation of these data should include a consideration of our limitations. The measures utilized for this study are self-reports and subject to the potential shortfalls of this type of data acquisition (Rust & Golombok, 1999). We used self-report instrumentation, but in-person clinical assessment is preferable, if much more costly. Non-response error is a potential concern; if non-respondents differ substantially on the variables of interest, our estimates are biased. Our survey was also cross-sectional; recall may be compromised for some respondents who experienced the death of a child many years ago. The sample is demographically homogenous and thus future research should focus on ethnic, religious, and socioeconomic diversity in the respondents. Despite the aforementioned methodological limitations, this study adds to what we know about bereaved parents participating in an online support community, and perhaps offers insight into the experiences of other bereaved parents who suffer enduring distress after the death of their child.

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